

FACTSHEETS FOR HEALTHCARE PROFESSIONALS:

Palliative Care for Individuals in Late-Stage Huntington Disease

There are many ways that healthcare professionals can improve the quality of life for individuals in the late stages of Huntington disease (HD), a fatal neurodegenerative disorder, and support family members during this emotionally stressful period.

Assessing needs

Assessing needs may be difficult if the individual's cognition and/or communication skills are affected. In these situations, simple communication systems (such as having the person touch your hand to indicate yes/no) may help. You can also use the Abbey Pain Scale (see "For more information" below), a checklist of non-verbal pain indicators.

Most importantly, get to know the person as an individual and pay close attention to symptoms.

Watch out for the following problems in the later stages of HD:

- Changing sensitivity to pain and temperature
- Aspiration
- Infections
- Loss of the swallowing reflex
- Malnutrition
- Dehydration
- Weight loss
- Reduced mobility

As well, watch out for signs and symptoms that could indicate infections or other problems that aren't related to HD.

Managing symptoms

In the later stages of HD, palliative care physicians and nurses should be involved to manage the symptoms holistically.

Seeing the person behind the disease

Although people in late-stage Huntington's are often unable to communicate, remember that they still deserve to be treated with dignity and respect. By taking a few moments to ask family members about their life history, achievements and personal tastes, you can offer more personalized end-of-life care.

Respecting care decisions

Make sure you know about any advanced planning directives and representation agreements/power of attorney for personal care and/or financial matters the person may have put in place.

Supporting the family

Family members need support from diagnosis through death and beyond. Keep in mind that the hereditary nature of HD means that the caregiver and/or other family members may be at risk of developing the disease themselves.

Families with Huntington's undergo repeated loss, making it difficult for them to find meaning or hope, so grief work is particularly important to deal with the cumulative trauma. Local bereavement support is often available through hospices and other organizations.

For more information

- Abbey Pain Scale
(http://prc.coh.org/PainNOA/Abbey_Tool.pdf)

- *A Caregiver's Guide for Advanced-Stage Huntington Disease*, Jim Pollard, Huntington Society of Canada

Adapted from: *Huntington's Disease Association's Standards of Care*, Huntington's Disease Association / St. Andrew's Healthcare
<http://www.hda.org.uk/download/fact-sheets/HD-Standards-Of-Care.pdf>